Mother granted time with ailing son through generosity of Army civilians

By: Mary M. Rall Alaska Post editor

It's difficult to imagine the energetic 4-year-old boy who was colleting handfuls of treats from candy machines and exploring every inch of the Fort Richardson Starbucks under his mother's careful watch Aug. 28 was fighting for his life just weeks before.

Caden John is a cancer survivor, and his mother, Schelly John, said a succession of what she deems miracles has given her the blessing of having her son with her today.

The day she'll never forget

The New Year began somewhat typically for John and her two children, Caden and Cameron, who were then 3 and 6, respectively. As an administrator with Fort Richardson's Child and Youth Services' Part Day Programs, she was getting back into a regular routine Jan. 3 following a vacation over the holidays with family in California. However, as the day progressed, Caden developed a 104-degree temperature that raised an alarm in his 29-year-old single mother.

"I will never forget that day," she said.

Although Caden was running a fever, John said he wasn't exhibiting any other signs of illness, such as a loss of appetite. Further, she had recently noticed some "spots" on his face, which gave her cause for concern. Taking action, she said she packed up Caden and brought him to see his pediatrician at The Children's Clinic in Anchorage.

According to John, a test for the flu came back negative, so she asked the doctor what the developing "spots" on her son's face might be an indicator of. She said the doctor thought it was prudent to run more tests, the results of which presented her small family with devastating news.

John said a phone call she received from the pediatrician that night was full of urgency.

"She asked me if I was sitting down," John said, adding her mother's intuition had been preparing her for the worst. As it turned out, she was right to brace herself, because Caden had been diagnosed with Acute Lymphoblastic Leukemia, a cancer of the white blood cells most commonly found in children.

The pediatrician instructed John to immediately take Caden to the Providence Alaska Medical Center in Anchorage, stressing she would meet her there. The next day, John and her son were medically evacuated to the Children's Hospital in Seattle, where she anticipated Caden receiving a few weeks of treatment to be followed up with care in Anchorage.

"I thought I could handle that," she said, explaining she had exhausted most of her leave on her recent vacation to California, but felt she would be able to financially meet the demands of being away for what she thought would be a matter of weeks.

Then the other shoe dropped

What was originally diagnosed as ALL turned out to be Acute Myelogenous Leukemia, John said, a more aggressive cancer of the blood and bone marrow most commonly found in adults. She said the diagnosis was frightening and presented an even greater challenge for her family, as Caden's entire treatment would have to be carried out in Seattle and would last months rather than weeks.

Cameron, who was staying with a family friend, was going to have to be relocated to Seattle to live with John at the Ronald McDonald House, and she said she had no idea how she was going to be able to avoid selling her home and car without an income over such an extended period of time.

That's when she said she saw signs of her first miracle.

The generosity of others

An e-mail soliciting help from fellow non-appropriated fund employees resulted in donations of about 300 hours of annual leave, John said, enough to carry her through for more than seven weeks. Caden's treatment was anticipated to last more than seven months, however, and John said she began to get nervous when the leave donations began to diminish.

"People can only donate so much leave. I didn't think there were enough NAF employees even up here," she said. "We're talking about seven months."

John said her friends told her to face reality — that she had no other choice but to give up her house and car. No one, they said, was going to be willing to donate enough leave to carry her through to the conclusion of Caden's treatment.

Undaunted, John said she refused to give up.

"I'm going to pray for a miracle, because I have worked damn hard for what I have — what I've accomplished as a single parent and my kids and having a nice home for them and a good life," she said of her mindset at the time. "I'm not going to give all that up and go through eight months of treatment and then come back up to what? Nothing?"

John said she then sent an e-mail to Fort Richardson's NAF Human Resources Office requesting a solicitation for more leave donations. She was overwhelmed by the response, which garnered more than 500 additional hours of annual leave, the equivalent of about four more months of time.

"I don't know who donated. I'll never know," she said. "I know that couldn't have all come from the people here just on Fort Richardson."

She said the generosity the donors displayed speaks volumes about their character.

"There's sadness when there's a child involved, and I guess that's why people (gave) with no questions asked," John said. "I think this shows that humanity is good."

Having that financial security allowed John to center her attention where it was most needed.

"It took so much pressure off, so much stress, and I was really able to concentrate and focus on my son and just help and staying positive for him – that was really hard itself," she said. "I didn't ever want him to see me cry or upset. I had to keep a smile on my face and stay happy no matter what – even when he was on his deathbed, and there were some times when he was really close."

The fight for life

Throughout his treatment, John maintained a Web log at cadenjfoundation.blogspot.com, through which she detailed the course of Caden's fight against AML and provided a means of keeping family and friends updated on how his treatment was progressing.

The contents of the online log illustrate the tough battle the little boy had to fight against a very big disease.

According to John's entries, Caden endured five rounds of chemotherapy, vomiting, weight loss, weakness, hair loss, seemingly endless tests and isolation among a host of side effects from his treatments. However, she said her son's a fighter who endured it all.

"At first it was a fight, and it was a struggle to take his blood pressure, his temperature, have him take his meds," John said. "He was on so many different meds at one point, it was insane. He didn't understand, and he fought; and I think because we were so positive we were able to stay positive for him."

John's mother, Cindy Frisby, traveled from California to join the family in Seattle and help provide support and care for the children while Caden was receiving treatment. She added to the blog as well, detailing what it was like to watch her grandson struggle with the deadly disease.

"It has been scary, we have been sleep deprived, I miss my home, the rest of my family and wasn't able to be with my dog Jacques of 15 years when he passed away," she wrote in a July 21 blog entry. "But, I wouldn't want to be anywhere else but where I am right now. I am so close to Caden and we have had some wonderful fun times full of laughter during these past 7 months! It has been fun being silly for no reason other than to make him smile and laugh."

Frisby said the experience was one that has left her forever changed.

"We don't know why this beautiful little boy has had to go through this experience except perhaps to change some of our lives. I know mine is," she wrote.

Following months of treatment, tests and worry, John and her family received news during the first week of August that Caden's cancer was in remission and he could look forward to going home.

"It was a miracle. It really was. I can't even describe it," John said, adding Caden's stay in the hospital ended with one of the most memorable moments of her life.

Frisby was with her grandson at the hospital when he was discharged, and John said Caden was so anxious to leave the hospital Aug. 14 he wanted to walk to meet his mother rather than have her pull the car up to the front of the hospital. Frisby called John, and they decide to meet up on the path that connected the Ronald McDonald House to the hospital. Minutes later, John rounded a corner and saw her mother and son.

"He sees me, and he's screaming, 'Mommy I'm better.' He comes running toward me with his arms open out wide," John said, describing the scene.

"He said, 'I'm free, I'm free. I'm out of the hospital," she said. "I picked him up, and I gave him a hug, and I told him, 'You did it, baby. You did it."

High hopes for the future

Thanks to the generosity of the NAF employees who donated more than 800 hours of leave, John and her sons have been able to return to their Anchorage home. Currently, John is preparing Caden to return to his former routine, which includes child care. However, Caden is still suffering the effects of suppressants that have weakened his immune system and must wait until Monday to return to a regular program at the post Child Development Center.

"My biggest concern right now is...the parents that drug their children up on Tylenol when they're sick and take them into child care because they have to go to work," John said. "That could endanger my son's life. It's exposing him to all these different illnesses and sicknesses."

She said although Caden will be ready to return to the CDC, it's important for parents to be aware of how their actions impact other children being cared for at the facility.

"It's real important that the parents know that we have a recovering cancer patient in the room who still has a weak immune system," she said.

Spending time with Caden as he expressed his enthusiasm for all things Star Wars, to include the bright red Lego Star Wars T-shirt he proudly displayed by opening his blue track jacket wide Aug. 28, it may be difficult to imagine him deathly ill or that he might still be at risk.

Unfortunately, John said there is still a significant chance he has not seen the last of AML, which has a 45 to 60 percent chance of resurfacing. However, she said she has experienced enough miracles since his diagnosis to have faith he will be OK and wants to thank those who contributed so much to her family during their time of need.

"I have no way to thank them or repay them except I chose to come back up here and work for NAF again. It's an organization I firmly believe in. Obviously I have great coworkers," she said. "They really came through. I mean, I was able to keep my home, my car; my bills got paid, I had my normal paycheck. I had extra expenses because it was down there and paying for everything up here, but I was able to make it work."

John said parents who have children receiving care at Part Day Programs also provide support that truly made a difference in boosting her family's spirits.

"I have some of the best parents at Part Day Programs — and that's another reason why I'm coming back — that sent cards and letters and care packages," she said. "It was awesome, and it proves that there are still good people in the world."

Editor's note: Schelly John's Web log and pictures of Caden's stay at the Children's Hospital in Seattle can be accessed online at cadenjfoundation.blogspot.com.